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**The meaning of 'Choice and control' for people with intellectual disabilities who are planning their social care and support**

**Running title: The meaning of 'choice and control'**

**Key words: autonomy, personal budgets, relational autonomy, choice and control, support planning, intellectual disability**

## **Abstract**

*Background* This paper questions consumerist assumptions in current English social care policy, and aims to look behind the processes of personalization to interrogate what ‘choice and control’ means in the lives of a diverse group of people with intellectual disabilities. *Methods.* Data was from multiple interviews and direct practice recordings with nine people using personal budgets, and were analysed using an interpretative approach. *Results* Identity, other people and personal budget processes were all important for choice and control. People needed to build confidence in themselves as decision makers, both through peer support and through joint decisions with trusted others. *Conclusions* Practitioners need to take into account the spectrum of ways in which people may make decisions. Action needs to be taken both at the micro level of support interactions and at the macro level, with a clearer articulation of independent living in policy and strategy for people with intellectual disabilities.

## **Background**

UK Government policies about social and health care foreground notions of ‘choice and control’, sometimes bracketed together (Department of Health, 2005: 33) and sometimes separately. Both these terms are generally defined in terms of the individual’s relationship with their support services, challenging the status quo of protective, authoritative social care which rigidly controls a disabled person’s life (Department of Health, 2005; 2007). For instance, personalization is defined as service users having

‘choice and control over the care and support they need to achieve their goals, to live a fulfilling life, and to be connected with society’ (Department of Health, 2012: 18)

With a slight twist in emphasis, the 2014 Care Act, discusses the notion of ‘control’ over day-to-day life, seen as one element of ‘wellbeing’, which is cited as the primary goal of providing social care (Care Act 2014: 1). In a related vein, a consumerist model of choice has long been promoted, particularly in social care services (Department of Health, 2005), and this has been

reflected structurally in the systems for accessing social care (Glendinning, 2008), with direct payments being introduced in the UK in 1996 (Community Care & Direct Payments Act, 1996). Policy tropes such as this are generally introduced as a reaction or a critique to the status quo, and in this case, 'choice and control' discourses are set up in contrast to the previously unquestioned relationship of provider and recipient, enacted between disabled people and the state.

The drive towards choices and consumerism in everyday life in Western societies is not without its critics, with popularist commentators such as Schwartz (2005) and Saleci (2010), questioning whether an array of choices necessarily leaves us more fulfilled as human beings. Schwartz (2005) points out succinctly that too many choices can be bewildering, time-consuming and ultimately may make us feel inadequate, an important point to bear in mind when exploring these issues with people with intellectual disabilities. 'Choice and control' in social care have thus been modelled on a widespread but maybe inherently flawed consumerist model of choice.

The ability to make an informed decision, as a rational human being, is nevertheless embedded in Western societal values and Johnson, Walmsley & Wolfe (2010) have argued that this type of individual, rational autonomy can come to define what it means to be human. By contrast, models of decision making which incorporate human relationships and interdependence have long been proposed (Jenkinson, 1993; Bandura, 2000; Wilson et al., 2008). More recently, these ideas of relational autonomy amongst people with intellectual disabilities have been examined in quantitative research by Wehmeyer and Bolding (2001) and Smith (2013) gives the concept of interdependence a more general reach:

*It is better to describe all persons, whether or not impaired, as 'interdependent', rather than either independent or dependent, which then allows agency, autonomy and choice*

*to be promoted as a matter of degree for everyone, recognizing how complex social structures and institutions facilitate this process for all* (p. 29)

These ideas of interdependence resonate with definitions put forward by the disabled people's movement (Morris, 2004) which frame autonomy as a matter of control, rather than simply as isolated independence. However, the big idea here was always that people could be *in control* of decision making, without necessarily being able to do things *functionally* for themselves – it is that notion of interdependence which led to the campaign for Direct Payments in the 1990s in the UK (Zarb and Nadash, 1994). Additionally, for people with intellectual disabilities, Finlay, Walton *et al.* (2008) and Author (2011) show how this type of autonomy-with support depends heavily on the skills, interactions and behaviours of others in the environment.

The mechanisms for delivering 'choice and control' have regularly been put under the research spotlight. There has long been evidence for instance that direct payments are associated with greater feelings of control amongst service users (Leece & Bornat, 2006; Stainton & Boyce, 2004). However, only a minority of people with intellectual disabilities benefited from DPs in the early days, owing to difficulties in managing service provision in one's own right (Gramlich, McBride *et al.*, 2002). People with intellectual disabilities are in a particularly difficult position, since their presumed *incompetence* can be part of the basis for their eligibility for social care in the first place, and Author (2006) has been part of the movement to challenge this position, often by research which is carried out with and by people with intellectual disabilities (Gramlich *et al.*, 2002; Author *et al.*, 2009). The original barriers faced by this group were always about attitudes, underpinned by the assumption that being 'willing and able' were intractable hurdles for people with ID (Author *et al.*, 2006). With the advent of PBs, and also the implementation of the Mental Capacity Act (Author including others, 2015), people with intellectual disabilities, their families and their allies have at least been enabled to mount a challenge to the ways of life and the institutional practices that oppress them for instance in 'assessment and treatment units'

(Flynn, 2012; Bubb, 2014). Independent living offers the opportunity to forge personalized services for individuals, which enable them to have support tailored to their individual needs, and we have explored elsewhere (Author, 2011) how everyday interactions can be both empowering and supportive of the autonomy of people with intellectual disabilities.

The benefits of having a personalised lifestyle and support service however seem to often be confused with the notion of ‘consumerism’ as a basis for choice and control, leading to research that takes a critical edge about personalisation in general. In that vein, Glendinning (2008) reviews the evidence for social care consumerism, problematizing the development of a quasi-market in social care, but nevertheless arguing for the value of ‘choice and control’ as *outcomes* rather than *process* issues for disabled people. People’s lives are considerably enhanced by taking an active role in co-producing their own solutions (Boyle & Harris, 2009). Through this body of research, what emerges is a picture of disabled people experiencing enhanced satisfaction with their own lives, precisely because of the ways in which they are able to direct and manage their own services.

However, this type of discourse again sidelines certain groups of service users. Fine & Glendinning (2005) point out that the individualistic goal of autonomy might be unrealistic for many older people, especially those with cognitive impairments (Goodwin, 2011). Particularly with respect to people with an intellectual disability, the ability to benefit from the new schemes of neoliberal, consumer controlled supports is regularly cast in doubt (Dowse, 2009; Kendall & Cameron, 2013). Instead of envisaging people as individual choice makers, maybe we need to return to the ideas of independent living (Morris, 2004), and challenge the ‘pass or fail’ ideas of capability for individual autonomy. In that context, the notion of relational autonomy, as described above, is as relevant for people with intellectual disabilities as it is for older service users, and it is this concept also emerges in the current paper.

The move towards universal personal budgets was introduced in England to directly benefit *all* disabled people, including those who may be expected to experience difficulties in being DP users. However, in relation to people with intellectual disabilities, the evidence for success as PB users is also less than clear. Empirical research reviewed by Harkes et al. (2012) has revealed scant evidence of the benefits or drawbacks of self-directed support for people with intellectual disabilities, although Hatton & Waters' (2007) survey included 114 people with intellectual disabilities, with 72% overall saying they had more choice and control. Similarly, 240 people with an intellectual disability (25% of the total sample) were included in Glendinning, Challis, Fernandez et al's (2008) evaluation of Individual Budget pilots, which found that those in the individual budget group were more likely than those in the comparison group to feel they had control over their daily lives. Surveys however are often rather blunt instruments, when it comes to understanding *how* phenomena are experienced. Direct questions about choice and control often produce acquiescent responses (Heal & Sigelman, 1995) and in general, certain forms of preference organization in conversation can promote a bias towards solidarity (Clayman, 2002; Hayano, 2014: p. 405). By contrast, the current paper aims to achieve a greater understanding of choice and control, not by direct questions *about* choice and control, but by exploring data about people's experiences of the processes involved in personal budgets.

The widespread introduction of personal budgets in England has heralded some new notions of user choice, and elsewhere (Authors 2013a) we have argued that the support planning stage of the whole process is potentially the most important site for choice and control to be exercised, since this is the point at which the budget is developed into a plan, theoretically at the discretion of the service user. In order to deliver 'choice and control', practitioners may need to re-invent their own roles, despite the confusions and tensions this may encompass (Lymbery, 2012;

Manthorpe, Jacobs, Rapaport et al., 2009). We have also argued (Authors, 2013a) for a differentiated and sensitive model of support planning, gradually moving from a 'hand-in-hand' towards a 'hands-off' approach, recognising that PB users have a wide range of different needs and backgrounds, and will require different levels of facilitation.

This paper by contrast moves on from the practice and process issues relating to personal budgets, in order to see if we can learn more by understanding better the ways in which choice and control are constructed as meaningful phenomena in the lives of by people with intellectual disabilities.

## **Method**

The data in this paper consist of 14 semi-structured, qualitative interviews and three recorded support planning sessions with nine people with intellectual disabilities, and were collected in the context of a wider study about support planning, which included 23 participants over five local authority areas (Authors, 2013b), all of whom had some form of complex impairment and would arguably need specific support to make decisions about their personal budget (PB).

Support planning in our study was defined as all the decisions that help to determine how a budget will be put into action (DH, 2008). The nine people in the current analysis were chosen because they all took part at least in sections of interviews on their own behalf, giving us a sense of what they wanted from their lives and what was important to them. Family carers were present in four cases and we were very interested in their contribution and viewpoint, having focused on that elsewhere (Author et al., in press). However, for the purposes of this paper, we have tried to bracket the carer voice, focusing instead only on passages where the disabled person was contributing, even if that was done jointly with their family carer.



As our interest here is to understand the individual experience of ‘choice and control’, we have chosen to interrogate the data using the lens of interpretative phenomenological analysis (IPA: Smith, Larkin et al., 2009). IPA purposely focuses on a small number of cases, in order to develop an idiographic picture of each person, before considering both the congruences and the differences within the cohort. The interest is both in how each individual constructs their world, and also whether there might be commonalities or lessons to learn from the whole set. Our sample in this paper represented a reasonably wide spread in terms of cognitive and communicative ability, ethnicity and gender. Brief details are given in Table 1.

An interpretative understanding of data recognizes that the analysis is bound to be developed from the researcher’s own viewpoint, and so Smith et al. (2009: 34-37) suggest that this entails a ‘double hermeneutic’ where the researcher’s own sense-making is used as a mirror to reflect the sense-making of participants. We annotated transcripts and used memos to explore *why* things were said, and also *how* they were said, before developing a line-by-line coding system for each transcript in turn. For instance, one participant (B19) returned several times to a discussion of how she liked to go swimming ‘at the deep end’, despite her epilepsy, and would use her support worker to keep safe. Drawing on ideas about planned risk taking, the metaphor in the data tied in for us with the way she seemed to portray her own identity, as someone ‘at the deep end’ of life. Having developed individual codes, these were grouped together under superordinate themes for each participant, before examining the nine analyses side-by-side, to think about overall cross-cutting connections between our nine sets of data. Due to space constraints, we discuss the participants in this paper as a whole group, in order to analyse the common and the individual (conflicting) themes that emerged from these nine people. However, the aim is to ensure that we differentiate and examine the main categories that emerged for each person. We aim to give a flavor of what mattered to these nine PB users with intellectual disabilities, as well as presenting and discussing our findings about the group as a whole. All

names in this paper are anonymized, and details which might identify particular people are omitted or altered.

Ethical approval was given for this project by the English Social Care Research Ethics Committee. Informed consent was an issue, since several of our participants would be expected to have difficulties understanding research information. We therefore provided information in an easy-to-understand format (Rodgers & Namaganda, 2004) and reinforced this at our first meeting with each participant. The researchers also adhered to the Mental Capacity Act guidance in assessing whether participants had the capacity to consent to the research, and for those who did not, personal consultees were asked to decide about the participant's involvement. One person was lost to the study in this way, since he lacked an independent personal consultee, and despite following up with the local authority, we were unable to make contact with a suitable institutional consultee. Those who could consent for themselves were enabled to ask questions at the start of each interview, and to clarify verbally the purpose of the research.

## **Findings**

### ***Individual portraits of participants***

In this first section, we give three pen portraits of individuals – each one is an anonymised amalgam of three people, and between them they represent the spread of lifestyle, ability level and autonomy amongst the nine participants. Following this, we group the findings about choice and control into three sections, relating to a) identity; b) other people; c) the processes of the personal budget.

**Robert** came over as a hesitant individual, always anxious to please. He was nearly 60, and attended a day centre, but thought of himself as a volunteer there, and enjoyed the work

opportunities afforded to him. He had previously had a job, and clearly missed the status of being an employee. All his talk centred on support staff, at the day centre and at home, and he saw these people as potential 'friends'. He lived in his own flat, but had recently had to start having support staff for his own safety and protection; he found this very hard, and desperately wanted to explain what type of support suited him best, and indeed which support staff he most wanted in his life. Since he had no immediate family supporting him, he had been allocated an advocate whom he had worked with over some months. She helped him to express what he wanted in his support plan, but otherwise, he saw and described the PB process as a series of people-events, where he came into contact with significant folk who told him what he might want in his life.

**Mel** was a member of a self-advocacy group. She was in her thirties, and had started to employ her own staff through a direct payment, with some advice and guidance from 'role models' she had met in the self-advocacy group. Although her parents lived fairly nearby, she wanted her own life and saw herself as a young person just like anyone else, catching up with friends and pursuing her own interests, which included swimming. Like others in the self-advocacy group, she had found the kind of support she received for her PB quite challenging at first. She had not wanted to be pushed into total 'independence', and was happy making decisions with her support staff and personal assistant (PA) to help her. When we met, she had just moved to a new direct payments support provider, and was happily planning some college courses to develop new computer skills.

**Janine** was in her forties, and had always lived with her family. She had started receiving support from PAs, which she very much valued. They enabled her to do things independently from her parents, and not to feel that she was a 'burden' on them. Nevertheless, she did have significant behavioural, communication and physical difficulties, and her parents managed her direct payments for her, choosing to buy in support from an agency. There had been no mental capacity assessment in her case, although in all but name, her parents were fulfilling the role of

'suitable person' by making decisions about her support and care on her behalf. When it came to support planning, she did have views of her own, and wanted to get work experience and earn money to live with her boyfriend. However, these dreams seemed unrealistic to others in her life, and so she had been encouraged to accept a day service place which would assist her to learn communication skills.

*Insert Table 1*

## **Identity**

*Insert Figure 1*

'Being worthy of support' was an explicit concern for Robert and the other older people in the group, who had used support services for most of their lives. The implication was that social care support could in fact signal a type of 'discredit'. Another participant, Lisa, for instance constantly sought reassurance during her interview '*And how do you find me – what's the bad bits you've come across*' (Lisa, Interview 2). This moral stance towards one's own identity as a service user can play out differently. All the participants, in various ways, demonstrated in their interviews how they relied on praise and encouragement, and when this was not forthcoming, they became anxious or unsure of themselves. This trait was less evident in the three people who were members of self-advocacy groups, but nevertheless they too received ongoing supportive feedback about their choices from their personal assistants.

These identity issues lie at the heart of achieving a sense of choice and control. Seeing oneself as a potential source of trouble, and the product of other's judgements, clearly pulls against the possibility of taking some control over one's own decisions. However, the analysis revealed a continuum from those who portrayed themselves as passive 'objects' of the gaze of others, towards those who more confidently portrayed themselves as active agents in society. Moving on from Lisa and Robert's self-identity as potential problems, there appeared to be a stage of

resistance, in which participants were aware of the possibility of conflict, but avoided it. Janine, for instance, who lived with her parents, said: *'I'll just say yes (to her parents) because I don't want conflict'* (Janine, Interview 1). That type of comment revealed some awareness of the movement towards being an independent thinker. During an observed (recorded) support planning session, Kia reacted negatively to the discussion of 'outcomes', saying 'no outcomes' (Kia, observation 1). She saw outcomes as linked entirely with education and self-improvement.

Judging from their descriptions of how they had dealt with problems in their lives, others had also successfully resisted and gained confidence in their own right to resist. Both Mel and Fiona had found the type of support they received from a disabled people's organization rather difficult, and they had found help through their self-advocacy organization to choose alternative direct payments support services. The three self-advocates had overcome the idea that they alone constituted the 'problem', and were confident enough to seek changes in the structures around them. Fiona in fact challenged her PA's construction of what had happened, and insisted that she did feel a sense of control:

*I've got control. You know, me and [my PA] can sort of sit down and we'll work out dates and that.* (Fiona, Interview 1)

Somewhere along the road towards greater confidence, there seemed to be an essential stage, in which people understood that they had the right to be themselves. Unfortunately, that was continually eroded by the very system there to support them, in that they were considered to be improving themselves, learning and developing new skills, as we explore further below.

However, the least cognitively able people in the sample (Kia and Khalil) who had considerable communication difficulties, were nonetheless able to demonstrate their pride in their own personality and interests. Khalil for instance talked about himself as a boyfriend, as a worker and a rugby fan: *'I've got a new jumper and a Tesco badge .... And my girlfriend'* (Khalil,

*observation 3*). Others such as Fiona and Tony also saw themselves as fun-loving people, seeking simply to enjoy their lives ‘in the moment’ and pursue their interests, which ranged from art to swimming. Fiona saw herself as a risk-taker, and particularly enjoyed describing how she went ‘*in at the deep end [of the swimming pool]*’ (Fiona, Interview 1).

Finally, an important identity theme was that of citizenship. In particular, the three people who had been members of self-advocacy groups, described happily how they helped other people with intellectual disabilities, and contributed towards society through voluntary work or within their family. Clearly, that type of peer support was vital to their own sense of being part of a collective, and offered them both a place for practical help which boosted their own pride in who they were:

*‘If we want to know something, we can just go to them [the self-advocacy group] and they’re 99.9% certain to know what you’re on about’* (Mel, Interview 2).

## **Other people**

*Insert Figure 2*

Closely allied with the identity issues, the theme of ‘other people’ seemed equally important to an understanding of choice and control. In the quote from Mel above, the sense of ‘we’ within the self-advocacy context was a strong feature of her talk – and that of other ‘People First’ members. A similar use of ‘we’ also permeated the talk about day centres, particularly amongst those who were long-term attenders. People mentioned at the centre, however, were principally the staff – and both Robert and Lisa spoke of the professional staff there by first name, and considered them to be potential friends and people to trust with problems:

*I’ve got Sandra now, really. Sandra and Jackie – because Rick used to be here, but he’s not here much now. But – he’s over (name of place) And Sandra, I can go to Sandra with any problems I’ve got, really.* (Robert, Interview 1)

The question that must then be addressed is the extent to which personal relationships are conducted on a basis of equality. Those who saw their staff as friends did not always see *themselves* as active in decision-making processes. 'They' were portrayed as powerful others who would shape their own wishes, and one of these people spoke of his review meeting in the following way:

*I'll just listen to what they say. Listen to what they say, and if I agree with them or not agree with the questions. Just wait and see when I get there, I would say. I don't know until I get there. (Robert, Interview 1).*

This distinction between active, equal relationships and passive, power-imbued relationships, was not always clear-cut. There was another type of decision-making described (and indeed enacted) by participants who had close relationships with their PAs. They too tended to talk about 'we' rather than 'I'. Not only did PAs help them with day-to-day choices about activities, but helped them to solve problems about their PB, and to develop their support plans. Mel said that she asks her PA to 'take over' if things get too complicated, and Tony was used to working out the rota for his PAs jointly with his lead PA:

*I've got control. You know, me and Pamela can sort of sit down and we'll work out dates and that. (Tony, Interview 2).*

Tony's PA, who was present in an interview, produced some information about a college course which Tony might wish to pursue, since she knew he wanted to improve his computer skills and gain employment. The pair also described how the PA had been actively involved in helping Tony to find a new house, and to move, and they lived relatively near each other. That level of personal and (to some extent, mutual) friendship was not universal with PAs.

Nevertheless, support staff and PB user appeared to be jointly constructing decisions, and all the decisions mentioned were about the life of the disabled person. Despite this lack of reciprocity, for Tony and other self-advocates, this relationship was definitely portrayed as a positive.

However, being surrounded by those who know you very well can cut both ways. Four of the nine participants here were living with family members, and all were actively involved in their support planning. In the observed sessions (Author, in press), as well as the interviews, it was evident how a family member acted as a very strong advocate, and routinely took on the role of prompting, clarifying and repairing the conversation, since they all too often knew beforehand exactly what their relative was about to say! However, when there was any type of conflict between their views, family members definitely had the advantage in arguing the case, since they knew so intimately the circumstances of their family member. This only happened on very rare occasions, but it relates closely to observations of how decisions are shaped within other close relationships – including with the personal assistant (See Author, 2011: Chapter 7). For the most part, these close relationships were absolutely vital, from the descriptions given by participants. They spoke of the importance of ‘trust’, and Mel’s personal assistant described precisely how decisions could be made jointly with family members:

*Obviously if mum isn't too keen on something, as a mum, she will say, Look, hey, come on, do you really think that that's worth it? But she will never point blank veto it, you know?(Mel, Interview 2).*

The idea of ‘interdependence’ is thus multi-faceted. Although relationships were key to our participants, they played out very differently in the various contexts of their lives.



## Personal budget processes

*Insert Figure 3*

As indicated in the introduction to this paper, 'choice and control' in policy parlance are generally used as terms associated with the process of choosing and controlling one's own support services. In other words, they are part of the *process* of being a PB user. However, in the current data, this right to choose was not at all clear to participants. In fact, confusion was one of the first themes identified in the data. For Robert and Lisa (both older people in day centres), planning was often confused with the plan adopted internally within the centre, and neither they nor their supporters in the centre seemed clear about the word 'personal budget', although one had heard of 'direct payments' in the past. In both cases, the process of planning one's own support was identifiable only as a meeting, and the talk immediately turned to the people who would be present in that meeting. As seen above, Robert in particular took on a very passive role within that process.

An associated theme, which linked with the 'moral identity' notion above, was that of the assessment and review being a type of test of ability. People like Janine and Ben were both very happy to talk about the various skills they had achieved, and saw this as very relevant to their next planned support:

*Sometimes I buy Kit-Kat or Coke – anything, I just buy it with my money. I give the money to whoever works there, just give it to them. (Janine, Interview 1)*

Ben was also living with parents, but had aspirations to follow up his interests and considerable skills in music. However, having choice and control for him was tightly bound up with the level of college course which he could access, and so his ability to be a 'consumer' was of course limited by the menu of possible choices, and those in turn were limited by his previous

achievements. No wonder then that it is tough to develop one's sense of choice and control, when these PB processes are so interlinked with the notion that one's life is in effect a curriculum. In fact, when people did speak up about what they *really* wanted (marriage, employment) these aspirations were liable to be sidelined as 'only dreams'.

We were nonetheless told about, and were able to observe, some very happy relationships with support planners, both from the local authority and from independent disabled people's organisations. Apart from PA support in making these decisions, one person had benefited from a strong relationship with a social worker who had remained a 'constant' in his life, and there were other equally strong relationships with support planners from voluntary organizations. Having some choice and control in the process of a PB was clearly part of an ongoing close relationship with the support planner, who variously used strategies such as picture choice, and personal conversation about preferred activities, to develop an idea of what the person wanted in their life. In fact, one of these support planners came from an organisation which also provided for one-one and group activities, and so there was a sense that the support planner shared some of the passions for sport and art that were part of the person's plan. As her mother had previously explained, their relationship had built up gradually:

*Do you remember Mandy used to come and take you out, and you used to go up to the Rico for a hot chocolate, didn't you, and talk to Mandy about all the things you liked, and what you'd like to do if you had the money to do it and the support.*(Kia's mother, Interview 1).

Kia and her support planner also had a shared cultural and ethnic identity, which was emphasised in the conversation they had about particular foods and their shared liking for dance, and the resulting plan was clearly a joint production.

An interesting observation from all this was that, despite the lack of real engagement with the PB processes, people clearly valued their own choices. One of the early themes was 'the

serendipity of choice', with one person describing the freedom he experienced in being able to go out independently, whenever he wanted to:

*'I'm quite happy on my own. The door's always there for me, I can always go out when I want to and do what I want' (Robert, Interview 1)*

Fiona, with her PA, also started the day by just having a think about the choices open to her, and then planned what she would do on a daily basis. Therefore, these day-to-day choices were in many senses the outcome of a process, in which the meta-decisions about direct payments, agencies and support staff were all taken jointly. It was only the three People First members who could express some understanding of these more abstract decisions. However, during the course of the work it should be noted that the People First group ceased to exist, due to lack of funding. This point will be taken up below in the Discussion.

The problem with this type of analysis is that it leads us to position people with intellectual disabilities as 'not able' to manage independently the business of being a social care consumer (Dowse, 2009). However, instead of seeing people with intellectual disabilities as different from others, we would argue that there is increasing evidence and critique of the idea of consumerism as a basis for social care, as explored in the introductory section of this paper. What was needed by all these nine people was a far more personalised approach which would understand the detail of their sense of identity, the people in their lives, and their day-to-day living, in order for them to build a continued sense of *control*. Choices were only any good for them if they corresponded with things they wanted to do – with their sense of who they were, and the take-up of these choices by peers with whom they identified. As Antaki and colleagues (2007) have shown, proposing activities and choices can be done in persuasive ways which undermine the competence of the disabled person. Building a sense of confidence in oneself

seemed therefore to be a prerequisite for exerting any 'choice and control' in life, and that confidence was clearly founded on trusted relationships with others.

Independent living, as defined by disabled people (Morris, 2004) has never meant that people have to be functionally capable of executing their decisions. However, that functional notion of independence was still very much evident in the assumptions underpinning support planning with these people with intellectual disabilities. Confidence in oneself as a decision-maker was thus pitted against the need for intensive guidance and help: to keep safe, boil a kettle, find one's way home, and even to stay alone in a house. It was only those who had started to separate their personal autonomy from their functional abilities, who seemed able to discuss their own decision making in a positive light. In sum, the basic qualities valued amongst those who supported decisions about a support plan were informality and the willingness to form close, constant relationships, matched with an element of reliability and informational knowledge about options available. This sounds very little different from other PB users whose views of support planning were explored in Author et al. (2013a). We will explore further below how these commonalities may form the basis for a renewed attempt to understand 'independent living' as a type of relational autonomy in the lives of people with intellectual disabilities.

## **Discussion**

Examining choice and control from the point of view of nine, diverse people with intellectual disabilities has revealed many differences in their experience, as well as some common underlying issues. In terms of relational autonomy, we could safely say that this analysis has strongly supported Smith's (2013) thesis that people commonly make decisions with others. That, however, is a simplistic and unrevealing statement; what is needed is clearly more information on exactly how autonomy can be viewed and supported as an achievement (Bekkema *et al.*, 2014), for particular individuals in particular circumstances, a common concern

across continents (Soldatic *et al.*, 2014). This research has shown how much people with intellectual disabilities valued the personal touch, with named professionals, chosen carefully because of their ability to build up a type of decision-making confidence. In other words, they could listen to the wider issues which people articulated, and translate those into specific, concrete steps towards a more 'fulfilled' life on the terms of the person themselves. Much of this has the ring of good person-centred planning (Dowling, Manthorpe *et al.*, 2006).

The positioning of personal assistants in this study also has practical implications. If a PA is the first person to whom one turns, when there is a choice to be made, then it is vital that those taking on the role can step back from their own interests to give impartial advice (see also Author *et al.*, 2009). Equally, there will be times when they cannot supply that impartiality, and so they need at that point to call in an external, equally trusted source of advice. One of the problems in the system facing these nine people was that professionals in that wider, outside circle tended not to be constant. Social workers had to sign people off their books, and would have moved on between one review and another; advocates were allocated only to those with specific problems in their lives, and voluntary or user-led organisations were not always enabled to fill the gap. In fact, one of the biggest issues in the project overall was that voluntary sector organisations (VSOs) were losing their commissions from the local authority to assist with support planning (Author *et al.*, 2013b).

Peer support was also an interesting phenomenon (Williams *et al.*, 2013a). The definition of a 'peer' was clearly someone who identified with the label of intellectual disability, particularly members of self-advocacy groups, supplying confidence and mutual support. Being a self-advocate was not just about getting professional guidance; it was about contributing and helping others (Goodley, 2000). The value of self-confidence as an autonomous citizen cannot be overestimated, and that confidence was often gained by feeling that one had something to offer,

as well as knowing that one had the right to receive support. Therefore, the financial problems faced by self-advocacy groups, and in fact the closure of one which had been involved in this study, constituted major obstacles to the real opportunities for choice and control amongst this group.

For all those in receipt of a personal budget, the idea of 'support planning' is a central and important stage. The analysis in this paper fleshes out further the notion of a differentiated model, which we discussed in our previous work (Author et al., 2013a). However, the formalities of bringing people together in a meeting were probably the least important part of support planning for any of these people with intellectual disabilities. If people with intellectual disabilities are really to be included in government targets for 'choice and control', then we need to learn from their own experiences and lived understanding of those terms. Unfortunately, research has tended to be broad brush, and either to endorse or to criticize the PB process in relation to people with intellectual disabilities (Harkes et al., 2012). What we need, both in policy and in research, is some action both at the micro level of support interactions, and at the macro level of attitudes and understanding.

At the micro level, we need to ensure that the way in which decision-making is supported actually does respect the everyday, small choices which are so important to people with intellectual disabilities. Interdependency, as put forward by Smith (2013) is in a sense a truism, since the idea applies to the way in which all decisions are made. We all fail to make good decisions under repeated questioning about our plans, and particularly within interactions involving any disabled person, effective decisions are made by listening and engaging with what really interests the individual. Building confidence as a decision maker is the fundamental building block to becoming a PB user, and this type of confidence building needs to start with young people at or before the stage of transition to adult services.

At the macro level of meaning and attitudes, policy and strategy documents need to underline more clearly that independent living is not a 'functional test'. Challenging that assumption amongst people with intellectual disabilities is long overdue, and the right to be oneself will never be fulfilled as long as people consider they have to continually improve their skills in order to be capable of managing their lives.

## References

Author et al. (2006; 2009; 2013a and b; in press). Author (2011): Author (including others) (2015)

Antaki, C., Walton, C. & Finlay, W. (2007) How proposing an activity to a person with an intellectual disability can imply a limited identity. *Discourse and Society* 18(4), 393–410.

Bandura, A. (2000) Exercise of human agency through collective efficacy. *Current Directions in Psychological Science* 9, 75-78.

Bekkema, N., de Veer, A., Hertogh, C. and Francke, A. (2014) Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study. *Journal of Intellectual Disability Research*, 58 (4), 368-80.

Boyle, D. & Harris, M. (2009) *The Challenge of Co-production: how equal partnerships between professionals and the public are crucial to improving public services*. New Economics Foundation, London.

Bubb, S. (2014) *Winterbourne View – Time for Change. Transforming the commissioning of services for people with learning disabilities and/or autism*. NHS England: <http://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf> (accessed on July 15th 2015).

Clayman, S. (2002) Sequence and Solidarity. *Group Cohesion, Trust and Solidarity* 19, 229-53.

Department of Health (DH) (2005) *Independence, Well-being and Choice: our vision for the future of social care for adults in England*. Department of Health, London.

Department of Health (DH) (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*. Department of Health, London.

Department of Health (2008) *Good Practice in Support, Planning and Brokerage*. Department of Health, London.

Department of Health (2012) White Paper: *Caring for Our Future*. Department of Health, London.

Dowling, S., Mathorpe, J., & Cowley, S. in association with Sarah King, Vicki Raymond, Wendy Perez and Pauline Weinstein (2006) *Person centred planning in social care: a scoping review*. Joseph Rowntree Foundation, York.

Dowse, L. (2009) 'Some people are never going to be able to do that'. Challenges for people with intellectual disability in the 21<sup>st</sup> century. *Disability & Society*, 24 (5): 571-584.

Fine, M. & Glendinning, C. (2005) Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing & Society*, 25, 601-621.

Finlay, W., Walton, C. and Antaki, C. (2008) Promoting choice and control in residential services for people with learning disabilities. *Disability & Society*, 23 (4), 349-360.



Flynn, M. (2012) *Transforming Care: a national response to Winterbourne View Hospital*. <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

Glendinning, C. (2008) Increasing Choice and Control for Older and Disabled People: A Critical Review of New Developments in England. *Social Policy and Administration*, 42 (5), 451-469.

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M. & Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme. Final Report*. Social Policy Research Unit, University of York.

Goodley, D. (2000) *Self Advocacy in the Lives of People with Learning Difficulties*. Open University Press, Buckingham.

Goodwin, N. (2011) Can older people with cognitive impairments make effective choices about their health and social care? A commentary on Meinow, Parker and Thorslund from an English perspective. *Social Science & Medicine* 73, 1290-1291.

Gramlich, S., Mc. Bride, G., Snelham, N. & Myers, B. (2002) *Journey to Independence: what self-advocates tell us about direct payments*. British Institute of Learning Disabilities, Wolverhampton.

Harkes, M., Brown, M. and Horsburgh, D. (2012) Self Directed Support and people with learning disabilities: a review of the published research evidence. *British Journal of Learning Disabilities*, 42, 87-101.

Hatton, C. & Waters, J. (2007) Evaluation Report Phase Two of In Control's Work in 2005-2007 in *A Report of In Control's 2<sup>nd</sup> Phase: Evaluation and Learning*. In Control, London.

Hayano, K. (2014) Question Design in Conversation in *The Handbook of Conversation Analysis* (eds. J. Sidnell & T. Stivers), pp 395-414. Wiley-Blackwell, Chichester.

Heal, L.W. & Sigelman, C.K. (1995) Response biases in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research* 39(4), 331-40.

Jenkinson, J. (1993) Who shall Decide? The relevance of theory and research to decision-making by people with an intellectual disability. *Disability, Handicap & Society*, 8 (4), 361-375.

Johnson, K., Walmsley, J. and Wolfe, M. (2010) *People with Intellectual Disabilities: towards a good life*. The Policy Press, Bristol.

Kendall, S. and Cameron, A. (2013) Personalisation of adult social care: self-directed support and the choice and control agenda. *British Journal of Learning Disabilities* doi 10.1111/bjd.12069

Leece, J. and Bornat, J. (eds) (2006) *Developments in Direct Payments*. The Policy Press, Bristol.

Lymbery, M. (2012) Social Work and Personalisation. *British Journal of Social Work* 42, 783–792.

Manthorpe, J., Jacobs, S., Rapaport, J., Challis, D., Netten, A., Glendinning, C., Stevens, M., Wilberforce, M., Knapp, M. & Harris, J. (2009) Training for Change: early days of individual budgets and the implications for social work and care management practice. A qualitative study of the views of trainers. *British Journal of Social Work*, 39, 1291-1305.

Morris, J. (2004) Independent Living and Community Care: a disempowering framework. *Disability and Society*, 19(5), 427-442.

Rodgers, J. & Namaganda, S. (2004) Making information easier for people with learning disabilities. *British Journal of Learning Disabilities*, 33, 52-8.

Saleci, R. (2010) *The Tyranny of Choice*. London: Profile Books.

Schwartz, B. (2005) *The Paradox of Choice: Why More is Less*. Harper Collins, New York.

Smith, S. (2013) Liberal Ethics and Well-being Promotion in the Disability Rights Movement, Disability Policy and Welfare Practice. *Ethics and Social Welfare* 7 (1), 20-35.

Smith, J., Flowers, P. and Larkin, M. (2009). *Interpretative Phenomenological Analysis. Theory, method and research*. Sage, London.

Soldatic, K., van Toorn, G., Dowse, L. and Muir, K. (2014) Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme. *Research and Practice in Intellectual and Developmental Disabilities* 1 (1), 6-16.

Stainton, T. & Boyce, S. (2004) 'I have got my life back': users' experience of direct payments. *Disability & Society*, 19 (5), 443-54.

Wehmeyer, M. and Bolding, N. (2001) Enhanced self-determination of adults with intellectual disability as an outcome of moving to community based work or living environments. *Journal of Intellectual Disability Research* 45 (5), 371-383.

Wilson, N., Clegg, J. and Hardy, G. (2008) What informs and shapes ethical practice in Intellectual Disability services? *Journal of Intellectual Disability Research* 52 (7), 608-17.

Zarb, G. and Nadash, P. (1994) *Cashing in on Independence: comparing the costs and benefits of cash and services*. British Council of Disabled People, Derbyshire.

### **Acts of Parliament**

*Community Care (Direct Payments Act) 1996: Chapter 30.*

*Care Act 2014: Chapter 23*